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ABSTRACT

The case study describes a family residential service for three people with profound and multiple disabilities in Burlington, Vermont. The disabled individuals live with a couple and their two children who are also provided support services in the form of weekend relief and helpers for the late afternoon and evening period. The house is owned by a private investor. The disabled individuals are all in their twenties and had previously been institutionalized. The program is private and was set up at the instigation and support of faculty members of the University of Vermont's psychology department. The cost of the program is \$40,000 a year per resident which comes from Medicaid and the state. Each of the disabled residents is described as is a typical day. The program's philosophy is holistic stressing the making of a happy home. Also discussed are specific issues such as replication, ways of encouraging a cooperative team approach, and costs. (DB)

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THE NO NAME PROGRAM: THREE
SEVERELY MULTIPLY DISABLED PEOPLE
WHO LIVE AT THE PETRONE'S IN
BURLINGTON, VERMONT

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The No Name Program:
Three Severely Multiply Disabled People Who Live
at the Petrone's In Burlington, Vermont

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Tony, the father of the family that is the subject of this case study told me, "What disabled people need is to experience the happiness of living in a good family." As he sees it, the problem with most professionals and bureacrats who work with the disabled is that they don't understand that. To them everything they do is in terms of programs and learning modules. The solution to everything in the human service system is a program. Programs are a way of thinking that make people into clients, not into respected human beings.

Tony doesn't want to use the word "program" for what he, his wife, two young boys, and friends are doing. The form that nominated them for study was filled out in the place that asked "Name of the Program?," with "No Name - It is a Home." Out of respect for their way of thinking, in this report I try not to call it a "program," but in pursuing that goal I realize how entrenched the human service vocabulary is, and how it is difficult to see the world without using that frame.

Overview

Tony, his wife, Mary, their two young sons, and three severely and profoundly multiply disabled people live in a lovely new (four-year-old) home in a residential neighborhood in Burlington, Vermont. They have been there for four years and plan to stay there. They do not have any intentions of moving or changing their relationship with the disabled people whom they consider to be

part of their family. The house, which was designed and built specifically for the purposes it is being used for, is owned by private investors who teamed up with project to both "do good" and make a profit.

Mary has no outside employment and Tony works half-time on the staff of the psychology department at the University of Vermont. A network of friends and associates from the University are involved with the house. In addition, there are two people who are paid who come to the house in the late afternoons and stay until Molly, Ben, and Lisa, the three disabled people who live with the Petrones, go to bed. There are two other staff who live in the house on the weekend. Tony, Mary and the boys usually leave Friday nights and return Sunday nights. They are building a home--a retreat--about one hour drive from Burlington. Their dream of building their own place is almost done.

While all residents have made significant progress since moving into the home, Tony and Mary do not dwell on the "teaching" part of what they do. The goal of the family is to have Molly, Ben, and Lisa be part of it. Sure they teach them, but that is not an obsession.

Because of illness, doctors appointments and a variety of other intrusions, one of the three disabled family members is usually at home during day but all are in a day program that takes them from the house six hours a day.

The House

The house doesn't stand out on the residential street it is

located on except for the fact that it is the last house on the street and there are more cars parked outside than most. The street ends with a round-about, giving them plenty of excess parking for staff and other visitors. There is a Weber-like grill outside. The yard work is done by family members. When I visited, Mary's brother was visiting and was working on the lawn project.

The homes in the neighborhood are in the \$90,000 to the \$120,000 range and the house that the Petrone's live in is in the upper range. It has probably appreciated significantly in value since it was built in that it is located close to the University and in an area that is bustling with development. For the businessmen who invested in it it probably was a good deal.

Unlike other houses that they might have bought pre-constructed, the Petrone house was designed for what it is being used for. The fact that it was built to be the home of three profoundly handicapped adults and the Petrones is not evident from the outside but it is a little larger than most houses on the street. It is like a large ranch with two full baths on the first floor. One of the baths is equipped with a easily accessible whirlpool and wheelchair accessible shower. These are used extensively for the disabled family members. The kitchen, dining and living room form one large room. This large room allows for the many activities that occur in the house to take place in the presence of other family members. Those who are preparing the meal are in hearing and seeing range of those

sitting at the dining table and over on the couches in front of the TV. A fireplace in the middle of the space breaks the room up to provide a homey space. The sink and other aspects of the kitchen are all wheelchair usable. Over this large area is a bedroom and another small room that Tony and his wife and boys use as sleeping quarters. The house is comfortable and convenient, not luxurious or strickingly unusual.

Unlike other cities in the state, Burlington is a real cosmopolitan modern city. It is a mecca for yuppies, its economy is expanding and it has many of the trappings of attractive Eastern cities, good resturants and cultural events. It is within short driving distance to the best skiing in the East and a modern airport makes traveling to other major cities in the East easy. It is not far from Montreal. All these things combined with the fact that it is located on Lake Champlain, in the Mountains and surrounded by some of the most beautiful farm land in the country, makes it a very attractive place to live. People who live there appreciate their environment, know that they have more than most people have and are generally spirited about their lifestyle. This adds a positive tone to the Petrone enterprise.

Molly, Ben and Lisa

All of the disabled people who live in the Petrone house are in their mid-twenties, have been institutionalized for long periods of their lives, have had significant health and behavioral problems, and appear to be well-adjusted and happy to be a part of this family. All of them represent a class of people

that those who claim that not all disabled people belong in the community point to. All were in the Burlington Convalescent Center, a total institution, prior to moving in with the Petrones and were in danger of being dismissed from that facility because of the management problems they posed for the staff.

When doing descriptions of disabled people one always has to ask: "From whose point of view am I describing them?" There are fat files filled with clinical information about each person in the Petrone home, but the Petrone's don't emphasize that information in thinking about or describing these people they have come to love. Instead, they pick aspects about them that they like, those things that make Molly, Ben, and Lisa enjoyable. While the files might mention that they are not toilet trained, Tony and Mary would not think of describing them like that. They think of Molly as having a good sense of humor and as pretty. Ben is appreciative and good at putting up with the cold winters. Lisa is a person who has made remarkable changes in a short period of time.

Those who wanted to paint a picture about how helpless and unmanagable the disabled residents were or are they would have a lot of material in their files to work with. Ben is described in his records as an unresponsive 25-year-old, profoundly retarded man who needs complete care. He also has episodes of irregular and difficult breathing and seizures lasting 30 to 60 seconds. Ben is small with his head disproportionately large compared to his body.

Ben was born one month premature and was diagnosed early as having cerebral palsy and epileptic seizures. He was admitted to the Brandon Training School in 1965 when his mother reported that she was unable to continue to care for him. There is little known about his parents and they no longer maintain a relationship with him. Efforts to involve them in his life have been unsuccessful. When admitted, he was diagnosed as having encephalopathy and functioning in the profound range, unable to walk, talk, or perform any self-care skills. He remained in Brandon for approximately nine years. According to the records, he did not participate in any educational or habilitation program due to the severity of handicaps.

Ben received a conditional discharge from Brandon and was moved to the nursing care facility in Burlington. He was enrolled in a public special education class for multiple handicapped youth for part of the time he was in the convalescent home. His education involved self-feeding and gross motor development. Ben's health is still extremely fragile. He is prone to respiratory infections and has had pneumonia twice in the last four years. He has had numerous episodes of respiratory distress. The Petrones have oxygen on hand for this.

Ben has made progress over the four years since being with the Petrone's. Prior to coming he couldn't feed himself, now he does. He is more attentive to what is going on about him and is beginning to communicate. His progress, undoubtedly affected by his periodic hospitalization, is described as sporadic. Tony describes Ben as "a very pleasant likable young man who gets

along with others in the home."

Molly has probably changed most drastically since becoming part of the Petrone home. She was born in 1960 in a small town 40 miles south of Burlington, the 7th of 8 children. There has been no contact between her and her parents in years. The mother lives in the southern part of the state and the whereabouts of the father are unknown. At two months of age Molly was diagnosed as having microcephaly and spastic quadrapellic with hyperplexia. She was admitted to the Brandon Training School at the age of 4. The records indicate that upon admission she was unable to sit unsupported and unable to perform basic self-care skills. The records indicate that, like Ben, the institutional staff judged her unable to participate in education/recreation/habilitative programs due to the severity of her disability. Psychological evaluations by Brandon staff label her profoundly retarded.

In 1974 she was conditionally discharged from Brandon and moved to the Burlington Convalescent Center. She was subsequently enrolled in a public school education program for multihandicapped youth which she attended until the age of 22. She moved into the Petrone home when it opened in 1982.

Molly has made steady and substantial progress ever since. She no longer has the frequent tantrums that characterized her prior to moving into the home. She has made significant progress communicating through a communication board. Perhaps it's her appearance that has changed most dramatically. Her hair is well-kept and styled and she wears a touch of makeup and stylish

clothes. She is pretty. Tony describes her as very motivated to learn, very interested in people and her environment, and very rewarding to work with.

The week prior to my visit, Tony had taken Molly to an awards banquet organized by the Burlington ARC honoring volunteers. Molly has been volunteering once a week with the agency and was chosen to receive one of the distinguished volunteer awards. Tony's description of the banquet shows both the nature of the joy he gets from his work the changes in Molly and the quality of her life.

First of all the banquet was over two-and-one-half hours of speeches and other formal goings on. While at another time and in another place Molly might have screamed and had tantrums and acted completely inappropriate in a difficult, constrained situation, she sat through the whole affair, up straight and observing those about her with enjoyment. She fed herself and had what Tony described as a great time. By the smile on Tony's face when telling the story you could tell that this was one of his finer moments of the year. For him to be there enjoying her enjoying such an affair was at the same time just taken for granted while boggling his mind. Molly, the screaming-microcephalic-profoundly-mentally-retarded-institutionalized-client-with-no-self-help-skills, was Molly, one of the Petrone family, one of the guests of honor at the banquet. Never. Why not? The joy of knowing people's potential.

Lisa is the third disabled person living with the Petrone's. Unlike the Molly and Ben, Lisa's parents are very much involved

in her life. In an interview with them they showed great appreciation of Tony and Mary for taking Lisa into their home. They feel that they could not do it, but that they can enjoy a supportive parental relationship with her now, something that was extremely difficult when she lived in other settings.

Lisa was born in Burlington in 1958 following a difficult delivery in which she suffered anoxia. She is the oldest of four. Early in her life her parents noted her delayed development. At three she was diagnosed as having cerebral palsy and was still unable to crawl. At ten she was diagnosed as being profoundly retarded and was admitted to Brandon State Training School. She was becoming more difficult to take care of.

She was a resident at Brandon for four years and then was moved to the Burlington Convalescent Center, where she was involved in a special education program like Molly and Ben. Prior to joining the Petrone's she was disruptive and engaged in rumination after every meal. She has stopped this. Of the three people involved as disabled family members I got to know Lisa the least. In a style typical of the program, Tony describes Lisa as having a warm, pleasant personality and being a real nice person.

Shortly after the home began and Molly, Ben and Lisa moved in, in 1982, all the residents and Tony were involved in a serious automobile (van) accident. Their van was run into. Ben sustained the worst injuries breaking two legs and cuts to the face. He was hospitalized for over two months and required an extended

period of recuperation at home due to severe bedsores and chronic urinary tract infections. After a lengthy law suit, each of the residents won a settlement with Ben receiving the largest amount. It was arranged that the money was to be put into an account under their names and it doesn't effect their support payments from the federal or state government. The use is restricted to providing "therapeutic services" not available to them through their normal programs.

Ben who is medically fragile and finds it difficult in the winter, takes a trip to Florida each year on the money. He always goes accompanied by one of the least paid staff members. They get a motel room right on the beach and soak up the rays. Tony smiles telling about this. After all, isn't that what both the staff person and Ben need and deserve? After all, isn't that what they would never get if they were living under different circumstances and if they had not been involved in the serious and tragic accident? Life always works out, bad becomes good; that is, if you look at life in the long term and you're optimistic. This is what Tony has in mind when he thinks of a good family. This is what the Petrone's strive for in the lives of all the family members.

Adminstration

The Petrone's are what are considered private service providers. They may be the only one in the state, since state money is not dispersed through private vendors but rather through the ten mental health centers around the state. They are not part of any state program, but rather set the program up at the

instigation and support of faculty members from the University of Vermont's psychology department. One person, Tom Mozell, in particular, has been an important force in that his personal friendship with the Petrone's as well as his philosophy of service are reflected in the house.

One-half of the money for the program comes from Medicaid and the other from the State of Vermont. Tony, Tom and the others who started the program made the case to the state for support. I spoke to a high-ranking state mental health official who was very enthusiastic about the program and is hoping to get other such arrangements started. The total cost of the program is approximately \$40,000 a year per resident, a significant sum, if you did not take into account the higher cost of their care in an institution prior to living with the Petrone's.

There is a board of directors which included the two psychologists who were instrumental in setting up the program. Everyone involved in the program emphasizes that they have no intention of getting any larger, becoming an agency. The belief of the Petrone's and the board is that decisions and administration has to be as close as possible to the clients. There should be at the maximum two houses per provider. After that you start having "programs" and the focus becomes something other than the clients.

The Day

The Petrone's get up around 7:00. Both of the boys have to get

to school and the early morning is spent preparing them and Molly, Ben and Lisa to leave. The developmentally disabled family members do not leave until around 8:30 when they are picked up in a van to go to their day programs.

Of everything I observed, the day program that Molly, Ben and Lisa were in was the weakest link. The program is run by the Burlington Mental Health Center in a large factory-like building in downtown Burlington. There are thirty other developmentally delayed adults in the program. Molly, Ben and Lisa are involved in what is called the developmental program. Its purpose is to improve their basic self-care skills. When I visited, Molly was in a large room with many other clients engaging in the activity of the time which was coloring. The clients are divided into small groups to participate in various "learning activities." While I wasn't able to do extensive observation, the program appeared to be like many I had seen with too many clients doing too few things with little purpose. There was a atmosphere of boredom in the air. The person who took me on tour told me that one advantage to the location of the program was that they were able to easily take the clients into the downtown area to work on buying and other basic skills. Undoubtedly some good things are going on there but compared to the life that Molly, Ben and Lisa are living in the Petrone's this seemed isolated and segregated, a program from another era.

It was through this program that Molly does her volunteering one afternoon a week at the ARC advocacy office. This seems to be a much more individualized and positive activity than what the rest of the Center provides. The Petrone's are not happy with what

the day program provides, but it does offer an out-of-the-house activity for Molly, Ben and Lisa.

The day program ends at about 2:30 and Molly, Ben and Lisa return home at about 3:00. They are greeted at the door by the afternoon staff members and Mary and Tony, if they are home. They spend the time between coming home and having their baths as snacking and having some quiet time at which time staff provide one-on-one attention. Then there is meal preparation, which Molly, Ben, and Lisa participate in, and a family dinner. Staff work with them on improving skills, but this is integrated into the family routine rather than being isolated activities. Then there is television, listening to music and then to bed, which is between 10:00 and 11:00 at night.

The daily routine is punctuated by family activities, visits from friends and the like. There are birthday parties and other holiday celebrations and shopping. On the weekends family members go on various outings.

Philosophy

The ideas and philosophy that guide the program are discussed and developed in conversations between Tony and Tom. Tom has been developing these ideas throughout his professional career as a psychologist. He teaches them and organizes various workshops that Tony participates in. The Petrone home provides an example for Tom to illustrate what he is trying to teach. The approach is what they call a holistic approach. Their primary goal, as mentioned in the introduction is to make a happy home,

to meet the needs of the clients. The idea seems simple but it is not. It is fundamental. What do people need to be happy, to grow and become part of humanity? That can be learned by trying to create it. According to them, normalization, the least restrictive environment, IEPs and instructional objectives skirt the fundamental issue.

One thing that Tony emphasizes in talking about what they are attempting is continuity. He says that he has seen it all too many times. People come into developmentally disabled people's lives full of energy to do something to help them, stay a while and then leave. The experience of clients is one disappointment after another. What people need is stability and people they can count on. That's what the Petrone's supply and that's what is needed the most. When talking about the people who live with him, he emphasizes how just now, after living with them for four years, he is getting to really know them. Most programs don't have staff work with the clients long enough to get past the superficial aspects of the relationship.

Although Tony has a master's degree in special education and is in the doctoral program in the psychology department at the University of Vermont, he does not see himself as a professional and is not into the status the professional system creates. This is part of his philosophy and part of the philosophy of the program--those who are involved are well read and educated in matters related to behavior modification and quality programing for developmentally disabled people, but they do not want to relate to the people they know in that way. Tony said that he

has no aspirations to be an administrator or to be a professional the way we have professionals today. He is not interested in becoming rich and important in the tradition of the professional. He thinks that an important person is someone who is nice, who is kind, who gives to others. He said that early in his life he decided that he was going to be actively involved with his own family. He was going to stay at home and be with his boys and his wife. He wasn't going to go out and run around after the prestige of some phoney career. He feels that that spirit needs to guide the life of caregivers. What Tony enjoys is being with the people in his house, watching them as they go through the day enjoying the life that he is creating for them. That's what a good life is, not going to meetings wearing suits and ties and creating large systems.

The Petrone's are talented and thoughtful people. One of the reservations one might have about the program's success is that it is a one or two person show-that the program is the people to such an extent that others could not do it. Tony thinks not. The problem with bureacracy is that it knocks what the Petrones have out of people. There are a lot out there who could do it, who want to do it, but no one wants to be the system's pawn. The department of mental health wanted to take over his home, make it part of their system. He told them they could do it but he didn't want any part of it.

If Tony wants to do anything beyond what he is doing now, it would be to help people to think that they could do what he is doing and enable them to do it. That doesn't mean that he would administer their activities. He doesn't trust systems, he only

trusts the good sense of good people left on their own to creativity and good judgment to provide for people in a way that allows them to maintain their own integrity.

Tony says that what he and his wife are doing is modeled after what he learned from his Italian family in Brooklyn. His grandfather worked hard and experienced the joy of his son graduating from college as if he had graduated. More people need to feel the joy of seeing that their family members live, not dwell on their own accomplishments. While Tony is young, in his thirties, he is critical of his own generation, or more accurately of what pop psychology has promoted. He says they have encouraged a society in which individuals believe that they are more important than those they help.

All this sounds terribly serious. One quality of the program that is its strength is that people laugh a lot. Tony is serious but he is also unpretentious and is quick to see the humor in situations, particularly his own.

Staff

The program operates under what is called the extended family concept. Whoever works in the program, whoever is involved in the lives of family members is thought of as people who care for each other and are working toward meeting each other's needs. Thus people who work in the house are thought of as family members. As Tony puts it when they advertise for someone to work and someone asks what the job description is he tells them, "The job

description is to do what needs to be done. To work together to help each other out as if it were your own family." The most important characteristic in hiring a person is that the person understands the idea of an extended family and wants to participate.

The backgrounds of the staff who work in the house are varied. I interviewed the two weekend workers as well as one who comes in in the afternoon. They were unanimous in speaking about how good it was working with the Petrone's and how they were treated with respect and dignity. They said that rather than being told what to do, as was their experience in other jobs, they were asked to do things and were active in participating in discussing what needed to be done and what was best for the house's over-all functioning. While their wages were low, they felt that being cared about and part of the family went a long way in compensating them for their efforts. They all expressed a tremendous sense of feeling that their work was meaningful in that they found the disabled residents loving and appreciative of their efforts. The Petrone's are proud of the fact that staff who have worked in the house stay a long time. They don't have the turnover that plagues other residential services. Those who have left keep in touch, as a family member would, and they always come to visit when they are in town. They always turn up at the annual holiday party.

Tony and Mary have a story of their own. They went to high school together in Brooklyn. Mary's parents moved to Vermont when she graduated. Mary eventually moved up and Tony started

visiting her. Both fell in love with the state. Tony went to an experimental college in New Jersey where the students were, as he described them, either white hippies or New York Blacks. When he started visiting Vermont his dream of building his own house and having a small farm began. His idea was to become a veterinarian and to settle in the State. Veterinary school did not work out and Mary and Tony found themselves in Chicago as live-in staff in a community residence for juvenile delinquents.

They gave that up to come back to Vermont and work in a group home for six adult mentally retarded women. He met the people from the Barre Mental Health Center and went through the Johnston Master's program, which he didn't care for because of its emphasis on behavioral objects and loss of sight of the residents. Eventually they met Tom. Tom had been thinking about setting up a family like the Petrone's and asked Tony and Mary if they wanted to do it. The answer was yes.

Issues

Many issues this site visit raises have already been brought up in the case study. Let me briefly mention them again.

One issue that could be raised is whether a program like this could be duplicated. How much of it depends on the efforts, insights, and skills of unusually talented people? Tony is probably overly modest in taking the position that what he and Mary have been able to accomplish is nothing unusual. Undoubtedly there are many such talented people who could be brought into

such arrangements. How do you find such people and how do you empower them with the confidence and motivation the Petrone's have?

Another issue has to do with the cooperative, genuine team approach the Petrone's and the University staff are engaged in. This seems to be all too unusual. How can such arrangements be encouraged? What needs to be done to redefine universities' priorities to institutionalize such teamwork?

The Petrone's offer more than a physical setting--they stand for an anti-bureaucratic approach to service delivery. Services for the developmentally disabled have become so bureaucratized that widespread de-bureaucratization seems unlikely. While Tony says he is not a professional he represents the best in that tradition minus the worst. Perhaps the issue that the Petrone home raises had to do with the redefinition of professional.

Undoubtedly the question of cost would be raised by some hearing about the Petrone's home. Can such expenditures be justified? Such spending is not questioned for services of far inferior quality in total institutions. Yet when we see people living so well while other people without severe developmental problems people on welfare, street people live such meager existences, it seems unfair. Tony would tell you, as he told me, that that is the narrow way of looking at it. Why take what the Petrone's offer from Molly, Ben and Lisa because others don't have it? The issue is not whether what they are getting is fair. It is what are our priorities as a nation. How can we get what they have for all?

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